

ON THE BRAIN

The Promise and Peril of the Patient Portal

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We logged into my mom's patient portal daily awaiting the result from a cerebrospinal fluid test that would help give us the greatest confidence in the initial diagnosis of Creutzfeldt-Jacob disease (CJD), a rapidly progressive, fatal neurodegenerative disorder. Her symptoms started curiously when we noticed that her slippers kept dropping off her feet when she was sitting at a high-top table and then slowly other minor symptoms of confusion and losing balance began our interaction with a neurologist. After being discharged from the hospital confirming no stroke or other emergent condition, we had lost the daily and varied communications received in an inpatient setting. The updates on her blood pressure, heart rate, and overall status were comforting in a confusing way during this uncertain and overwhelming time. I was serving as my mom's health care proxy and the patient portal became my window to her health. It felt like we were monitoring her condition in "real" time. It was a way to help us feel like we were doing something. We had the probable diagnosis based on an electroencephalogram, magnetic resonance imaging, and some blood tests and no scheduled follow-up visits to the neurologist because there is currently no treatment for CJD. We were not yet on hospice or even considering hospice because my mom had been a picture of health before the symptoms started.

We began looking to the portal as a source of hope. Hoping to see other blood test results to tell us she had some type of treatable infection or maybe she actually had cancer that would give us a chance at remission. I reflected at the time with my father about how in years before we would have had to keep calling the physician to ask if they knew anything else or if any tests had come in. We felt that the portal was truly serving its intended purpose of keeping us involved in her health care and making us a part of the team. One by one the results would appear in the portal but there were no calls from her primary physician or the neurologist to explain what we were seeing. In the past, I had received calls from my own obstetrician/gynecologist and primary physician after fairly routine results came in, although the protocol in this situation was much less clear. I believed that her physicians were reviewing the tests and then writing in notes for us to see as a way to keep us updated. I was later informed that those impressions were from laboratory technicians or specialists who read them.

As a person who is involved in health care research and a hospice volunteer, I felt somewhat comfortable looking at the medical information and searching the internet for an idea of what it meant. I also had the additional benefit of working in a medical school in a different health care system and could easily ask questions of my colleagues to clarify what I read. As the frequency of my searching and asking others increased, it hit me

that no longer was I connected to my mom's health care professionals. I started to believe that I didn't need anything from them but more information. The portal, instead of serving as a way to participate in her care, became a replacement for the needed communication and interpretation from her specialist.

My anxiety increased as my mother's condition deteriorated over the course of a few short weeks. She was displaying all of the characteristics of a person dying of CJD: she saw beautiful colors that she reached out to touch and scary images in the reflections of the pictures on the wall. Her legs were restless and she constantly pulled them up to her chest and put them back down and her arm jerked, sometimes violently. During this time, I feverishly and desperately searched for the definitive answer. In particular, I was looking for the result from the real-time quaking-induced conversion (RT-QuIC) test. This, being the most sensitive and specific cerebrospinal fluid test to diagnose CJD, would help bring me to acceptance that there was no way out of our nightmare. I became compulsive with the portal, not knowing when a new result would appear. I started to believe that it was my responsibility to comb her medical record looking to catch any new finding to alert the health care team. I accepted my job as the advocate for her care and maybe took that role too far with the help of the portal.

My mother passed away in her home after just 6 weeks. The last thing I fed her was butter pecan ice cream and the last song I played her was "Blue Moon," because she loved to watch the grandkids when they were young dance and run around the living room while this played. Her patient portal was closed the day after her death and it felt like a door slamming shut in my face. I felt isolated and had no way left to process what I still wanted to know about her condition.

Weeks after her death, my father was able to ask his primary physician who still had access to her portal for the result of the RT-QuIC test. I learned that an alternate test was run because only one lab in the entire US, the National Prion Disease Pathology and Surveillance Center at Case Western Reserve, would have been able to do this test, and her sample was not sent there. There was no cerebrospinal fluid left to test and we had already declined autopsy before my mom was buried. I felt devastated and distrustful of her health care team. As a colleague told me, this was not good, but also not uncommon; it's a systemic problem, a communication breakdown, a lack of awareness.

This experience has caused me to think about my own interactions with the health care portal as well as how other patients may interact with the portal. There is a note in my own patient portal that indicates patients may receive a result before their health care professional. Are there instances when a patient finds out

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that they have a terminal illness before a physician can speak with them? Could they learn that their kidneys are failing or the chemotherapy isn't working when they are alone?

I went back to my own patient portal knowing that I was probably an extreme "user" of the portal to see if there were any suggested ways to interact with the portal. There was not. I saw statements about how my privacy would be protected and the terms and conditions of use. I want there to be a warning label, "laboratory results seen here are one part of a patient's medical history and should be discussed with a physician before any conclusions are drawn." In addition, my portal did not include the ability to conduct secure messaging with our physician as may be common in other markets and that may have made a considerable difference for us.

I also reflected on my own advantaged position and clearly saw the disparity facing others who may have been met with uncertainty and confusion trying to weed through the results. How would those who have low health literacy or limited English profi-

ciency or a disability fare if they entered the portal during a time of crisis? If the portal was there to promote communication and partnership, education and practical directions could be provided for patients to use to interpret what they are seeing and in our case, what is not in the medical record. It may have been helpful to see a notice of tests that were run but whose results were "pending." When a new result is ready, perhaps a message to call the physician to discuss the finding could appear or a link to an information sheet to guide what the result does and does not indicate. At the very least, physicians could open dialogue with patients and families during medical crises about what they may see in the portal and when they will communicate after those findings arrive. I am grateful we had access to the patient portal and see it as a powerful and promising step forward in patient autonomy and as a tool to promote communication between patients, caregivers, and physicians, but the peril of undue anxiety, potential misinterpretation of results, and breakdown in communication may be unexpected adverse effects that deserve further exploration.

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